

FIRST REGULAR SESSION

# HOUSE BILL NO. 262

## 97TH GENERAL ASSEMBLY

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INTRODUCED BY REPRESENTATIVES WALTON GRAY (Sponsor), ELLINGTON, PACE,  
SMITH (85) AND NORR (Co-sponsors).

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D. ADAM CRUMBLISS, Chief Clerk

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### AN ACT

To amend chapter 191, RSMo, by adding thereto one new section relating to a sickle cell standing committee.

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*Be it enacted by the General Assembly of the state of Missouri, as follows:*

Section A. Chapter 191, RSMo, is amended by adding thereto one new section, to be known as section 191.117, to read as follows:

**191.117. 1. There is hereby established in the department of health and senior services a "Sickle Cell Standing Committee" as a subcommittee of the Missouri genetic disease advisory committee. The committee shall consist of nine members, as follows:**

**(1) The lieutenant governor or his or her designee, who shall serve as chair of the committee;**

**(2) The director of the department of health and senior services, or the director's designee;**

**(3) One member of the house of representatives appointed by the speaker of the house;**

**(4) One member of the senate appointed by the president pro tem of the senate;**

**(5) One member who has sickle cell disease or is a family member of persons with sickle cell disease;**

**(6) One member who is a licensed physician with experience in the diagnosis and treatment of sickle cell disease;**

**(7) One member with expertise in sickle cell disease research;**

**(8) One member with expertise in minority health; and**

EXPLANATION — Matter enclosed in bold-faced brackets [thus] in the above bill is not enacted and is intended to be omitted from the law. Matter in **bold-face** type in the above bill is proposed language.

17           **(9) One member from a leading sickle cell disease organization.**

18           **2. The members of the committee, other than the lieutenant governor, members**  
19 **from the general assembly, and department director, shall be appointed by the governor**  
20 **with the advice and consent of the senate. Members shall serve on the committee without**  
21 **compensation or reimbursement for expenses incurred.**

22           **3. The committee shall:**

23           **(1) Assess the impact of sickle cell disease on urban communities in the state of**  
24 **Missouri;**

25           **(2) Examine the existing services and resources addressing the needs of persons**  
26 **with sickle cell disease; and**

27           **(3) Develop recommendations to provide educational services to schools on the**  
28 **traits of sickle cell disease and their effects.**

29           **4. The committee shall include an examination of the following in its assessment**  
30 **and recommendations required to be completed under subsection 3 of this section:**

31           **(1) Trends in state sickle cell disease populations and their needs, including but not**  
32 **limited to the state's role in providing assistance;**

33           **(2) Existing services and resources;**

34           **(3) Needed state policies or responses, including but not limited to directions for the**  
35 **provision of clear and coordinated services and supports to persons living with sickle cell**  
36 **disease and strategies to address any identified gaps in services; and**

37           **(4) Replacing the genetic testing and counseling program eliminated due to lack of**  
38 **funding. The program was an hour-long workshop provided to schools on the traits of**  
39 **sickle cell disease and the effects of such traits.**

40           **5. The committee shall hold a minimum of one meeting at three urban regions in**  
41 **the state of Missouri to seek public input.**

42           **6. The committee shall submit a report of its findings and any recommendations**  
43 **to the general assembly and the governor no later than December 31, 2013.**

44           **7. After December 31, 2013, the committee shall continue to meet at the request of**  
45 **the chair and at a minimum of one time annually for the purpose of continuing the study**  
46 **of sickle cell disease in this state, the impact of the committee recommendations, and to**  
47 **provide an annual supplemental report on the findings to the governor and the general**  
48 **assembly.**

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